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ABSTRACT

This booklet was written to familiarize health and mental health professionals and paraprofessionals with the psychological and social problems associated with acquired immune deficiency syndrome (AIDS). It briefly reviews the realities of AIDS and describes the challenge that AIDS poses for health care professionals. A section on neuropsychiatric dimensions of AIDS infection explores the range of psychological suffering experienced by persons with AIDS and explains involvement of the central nervous system in the disease. A section on treating patients with AIDS or related conditions discusses needs of patients which go beyond medical care and suggests referrals to various service groups. Treatment considerations are presented for patients with AIDS and for patients who have tested positive for HTLV-III antibody or who have AIDS-related complex. Support groups and mental health referrals are discussed. The next section looks at the needs of health professionals who work with AIDS patients. A conclusion to the report briefly summarizes its main points and is followed by a section on further information which includes a recommended reading list, AIDS hotline telephone numbers, and telephone numbers to call when requesting AIDS information from state departments of health. (NB)

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COPING WITH AIDS

PSYCHOLOGICAL AND SOCIAL CONSIDERATIONS IN HELPING PEOPLE WITH HTLV-III INFECTION

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This pamphlet was written by Bette Runck, Science Communication Branch, Office of Scientific Information, National Institute of Mental Health (NIMH). Substantial contributions were made by practitioners treating people with HTLV-III infections, NIMH-supported investigators studying the psychological and social aspects of these diseases, as well as other staff of NIMH, the Alcohol, Drug Abuse, and Mental Health Administration, and other components of the U.S. Public Health Service, including nursing staff at the National Institutes of Health.

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FOREWORD

This booklet, prepared by the National Institute of Mental Health, is intended to familiarize health and mental health professionals and paraprofessionals with the psychological and social problems associated with AIDS, the Acquired Immune Deficiency Syndrome. Sensitivity to these problems is especially critical given the present lack of a vaccine or cure for AIDS. Only by care and compassion can the quality of life be made tolerable for those who are afflicted.

The conquest of AIDS is the highest priority on our Nation's public health agenda. With the discovery of HTLV-III, the virus that causes AIDS, we can look with optimism toward the day when we will have available more effective treatments and a vaccine to immunize the population. Also, the U.S. Public Health Service has under way a major public information program on AIDS. One aim of this program is to provide facts about the disease and its ramifications and, in so doing, to encourage informed decisions regarding personal behavior that are essential to controlling the AIDS epidemic at the earliest possible time. This booklet forms another part of that effort.

The patient care professionals who have been on the clinical frontlines since AIDS first appeared were an invaluable resource in the preparation of this booklet. Among the most important of those contributions was the reminder by nurses treating people with AIDS that some of their patients cope uncommonly well with this awful disease, drawing on wellsprings of strength that nourish other patients and staff as well. We hope that this booklet will help health professionals tap those inner strengths in all their patients.

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Director
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The Realities of AIDS

AIDS is an infectious disease with potentially devastating psychological consequences. The reasons are many:

- Seventy percent of all people with AIDS die within 2 years of diagnosis.
- To date, all but a small minority of AIDS patients are homosexual and bisexual men or intravenous drug abusers—individuals who already may be stigmatized and subject to social and job-related discrimination. Such problems multiply with a diagnosis of AIDS.
- Ninety percent of all adults with AIDS are in the prime of life—between the ages of 20 and 49—when people are not commonly prepared to deal psychologically with imminent death.
- The infections and malignancies that accompany AIDS can diminish and disfigure the body.
- The AIDS virus often attacks the central nervous system, causing symptoms ranging from forgetfulness to profound dementia.
- The course of AIDS is marked by a series of life-threatening episodes, such as infection with *Pneumocystis carinii* pneumonia.
- Few other diseases produce as many losses—loss of physical strength, mental acuity, ability to work, self-sufficiency, social roles, income and savings, housing, and the emotional support of loved ones. Often, self-esteem also fades in the wake of such catastrophic losses.
- The physical weakness and pain resulting from AIDS-related diseases diminish the patient's ability to cope with psychological and social stress.
- Treatments for AIDS-related diseases, which may palliate but do not cure, may themselves cause psychological symptoms, such as listlessness, depression, and anxiety.

Merely living with the threat of AIDS can be psychologically debilitating. For those who have developed symptoms characteristic of the syndrome, distress might be even more severe than for people who know with certainty that they have AIDS. Individuals who have no symptoms but who know they have been infected with the virus that causes AIDS sometimes find themselves immobilized by fear. And those who belong to the groups at high risk for AIDS face ever-growing problems caused by the public's fear of AIDS and the efforts of employers and insurance companies to protect themselves from its economic consequences.

AIDS and Related Conditions

The Acquired Immune Deficiency Syndrome (AIDS) is one of several clinical manifestations of infection with a newly discovered virus, human lymphotropic virus, type III (HTLV-III). *To date, most people infected with the virus remain in good health. Others have developed symptoms ranging in severity from mild to extreme. Manifestations of infection may include (in addition to no symptoms) nonspecific signs and symptoms of illness, autoimmune and neurological disorders, a variety of opportunistic infections, and several types of malignancy.

If the infection with HTLV-III progresses, the onset of symptoms (the incubation period) ranges from about 6 months to 5 years or more. Symptoms may include tiredness, fever, loss of appetite and weight, diarrhea, night sweats, and swollen glands (lymph nodes)—usually in the neck, armpits, or groin.

Some people infected with HTLV-III have many of the symptoms listed above but do not develop the defining characteristics of AIDS; their condition is usually referred to as AIDS-related complex (ARC). ARC can, but does not invariably, lead to AIDS. The diagnosis of AIDS depends on the presence of certain opportunistic diseases plus a positive test for antibody to HTLV-III. Laboratory tests which demonstrate profound immune dysfunction and loss of T_4 lymphocytes, support a clinical diagnosis.

*The International Committee on the Taxonomy of Viruses has proposed the name *human immunodeficiency virus* (HIV) for the AIDS retrovirus.

The Challenge for Health Care Professionals

Health care professionals, while trained to respond to the medical, surgical, and psychological needs of their patients, face added challenges in helping people with AIDS. There are two major ones: First, health professionals must learn to serve patients with a new and unfamiliar disease—to treat and comfort people with AIDS, who face great suffering and death, and to provide information, treatment, and solace to others infected with HTLV-III but with few or no clinical symptoms. Second, health care workers must provide this help while at the same time coping with their own fears and their own pain in caring for patients who do not get well or whose outcome is uncertain; adding to the strain is the need to be especially mindful of behaving respectfully and sensitively toward individuals who may be social pariahs. This brochure discusses both challenges faced by the health professional.

Generally, hospitals have followed one of two models in treating people with AIDS. Some have set aside specialized units designed to meet the unusual needs of people with AIDS; only those staff members who are comfortable working with AIDS patients serve on these wards. Other hospitals have found it more useful to follow the other alternative, the "scatter-bed" model, where AIDS patients are integrated with other patients in general medical wards. In either situation, hospital staff follow routine blood and enteric precautions to avoid contact with HTLV-III. Although many of these measures are familiar, caring for people with AIDS can nonetheless be emotionally threatening to professionals. Specifically, problems arise from the following:

- First, as noted, special emotional stamina is needed to care for people with AIDS, who, in what should be the prime of life, may be rapidly deteriorating and dying.
- Second, although much is known about the special circumstances under which HTLV-III is transmitted, some health workers unfamiliar with this evidence may still consider caring for people with AIDS as potentially threatening to themselves and their families. (Risk to them is minimal, as has been shown by studies of 1,472 health care workers who have had close contact with AIDS patients.)
- Third, AIDS patients are very sick and place unusual burdens on the staff because of the intensity of their physical and emotional needs. Some health workers have become overtaxed, fatigued, and overwhelmed by the intensive care required by patients with AIDS.
- Fourth, perceptions founded on fears and incomplete information about people with AIDS or a potential for contracting AIDS may impair a staff member's ability to care for patients.
- Fifth, some AIDS patients are infants and children, whose deteriorating condition can be especially emotionally draining for staff. Since some of these children have been abandoned by their parents, staff are likely to feel an added sense of responsibility for nurturing them.
- And sixth, health workers must deal with families and other loved ones who may be under stress that is even more severe than that usually faced by those close to dying patients.

With a thorough understanding of these problems, health care professionals can play a critical role in affecting the psychological outcome for people with AIDS and other types of HTLV-III infection.

This booklet offers guidance to health professionals in their attempts to cope with the challenge of this new disease. It speaks to the needs of both patients and staff. Where noted, the information is based on early results of research on the psychological and social aspects of AIDS. Clinical advice is collated from the experience of physicians, nurses, psychologists, and other health professionals who treated people with AIDS and related conditions during the first 4 years after the syndrome was identified.

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Epidemiology of AIDS

AIDS was first reported in the United States in mid-1981. By the spring of 1986, the U.S. Public Health Service had received reports of more than 20,000 cases. The Centers for Disease Control estimate that 1,000 new cases a month will be reported in this country during 1986. An estimated one million people have been infected with the virus that causes AIDS, but have no symptoms of illness.

Ninety-five percent of the AIDS cases have occurred in the following groups of people:

- Sexually active homosexual and bisexual men, 73 percent (some of whom also used intravenous drugs).
- Heterosexual men or women who presently abuse or formerly abused intravenous drugs, 17 percent.
- Persons with hemophilia or other coagulation disorders, 1 percent.
- Heterosexual contacts of someone with AIDS or at risk for AIDS, 1 percent.
- Persons who have had transfusions with blood or blood products, 2 percent.

Neuropsychiatric Dimensions of HTLV-III Infection

Ever since health professionals started treating people with AIDS, they have recognized that the disease exacts an emotional toll along with the physical one. Some psychological symptoms accompany brain infections that flourish in the absence of normal immune function. Others are reactions expected of patients who face death. Still others are related to the symptom picture associated with AIDS, the ostracizing of patients, and the mystery surrounding the disease.

Recently it has become apparent that, in addition to psychological reactions and organic brain conditions resulting from opportunistic infections,

some people with AIDS show symptoms of other types of neurological damage. HTLV-III directly infects some cells in the brain. Postmortem analysis and neuropsychiatric evaluation of patients with various stages of HTLV-III infection demonstrate that central nervous system involvement may be extensive in some patients. Some symptoms that appear to be psychologically caused may in fact be organic in origin and degenerative in course.

The Range of Psychological Suffering

Infection with HTLV-III causes extreme distress not only for most people who have been diagnosed with AIDS, but also for those who have other stages of HTLV-III infection. The onset of symptoms—persistent infections, malaise, swollen lymph nodes, or loss of weight—is typically accompanied by fear of developing AIDS, a fear that becomes more likely as knowledge about the disease spreads. The diagnosis itself brings a kind of relief for some. But in its wake, psychological symptoms reappear.

Anxiety and depression are most common. Distress is evident in the preoccupation with illness and imminent death characteristic of patients with cancer and other often-fatal diseases. The stress response at time of diagnosis may be marked by disbelief, numbness, and inability to face the facts. Patients are angry at the disease, at the discrimination that usually accompanies it, at the prospect of a lonely, painful death, at the lack of effective treatment, at medical staff, and at themselves. Those who see themselves as "innocent victims" of the virus—having contracted it, for example, from a blood transfusion—are particularly prone to anger.

In many cases, guilt develops about the disease, about past behavior and style of living, or about the possibility of having transmitted it to others. Sadness, hopelessness, helplessness, withdrawal, isolation, and other symptoms associated with depression are often present. Anticipating that the disease will progress inevitably to pain and death, many patients contemplate suicide. Some attempt it, but few actually kill themselves.

Because both social and physical assistance are needed, a strong network of friends and family is particularly important. But homosexuals and intravenous drug abusers who are estranged from their families may lack such support. Additional strain is created for persons whose gay lifestyle or drug abuse becomes known to their families only when AIDS is diagnosed.

Anxiety may take the form of tension, tachycardia, agitation, insomnia, anorexia, and panic attacks.

Denial—the psychological defense mechanism that creates a "blind spot" so that a person fails to recognize the reality of a situation—may alternate with realistic concern about the outcome of the disease. Concern may be replaced by exaggerated sensitivity and hypochondriasis. People with AIDS tend to interpret any new symptom as bringing them closer to death.

Research has demonstrated that persons with the so-called AIDS-related complex (ARC), a condition with many of the symptoms but not the defining characteristics of AIDS, suffer more psychological distress than those

with AIDS. (Some health professionals who have worked with both types of patient doubt this finding.) A more intense psychological reaction may result from the ambiguity faced by people with ARC—"Will I get AIDS and die?" They fear that each real or imagined change will finally result in a diagnosis of AIDS. Also contributing to their distress are the difficulties they encounter qualifying for entry into special AIDS support programs and for disability payments.

Experience with persons who have a positive test result for the presence of HTLV-III antibody is still limited. Psychologists predict, however, that anxiety and depression will be common. Confusion over the meaning of the test can significantly increase anxiety, even with a negative result. A positive result may erroneously be seen as diagnostic of AIDS, although no one yet knows what proportion of positive responders will actually go on to develop the disease. Patients may feel a sense of chaos, find it difficult to set goals for the future, and retreat into isolation because of fear of exposure to new infections and concern over transmitting the virus to others. For example, many are unable to invest in work or form close personal relationships.

Central Nervous System Involvement

Research and clinical experience have demonstrated that neurological involvement occurs in many, perhaps a majority, of people with AIDS. The most common central nervous system (CNS) impairment is a *nonfocal*

encephalopathy, characterized by early symptoms that are usually indistinguishable from depression. Forgetfulness and poor concentration are, within a matter of weeks or months, followed by psychomotor retardation, decreased alertness, apathy, withdrawal, diminished interest in work, and loss of libido. Later, some patients encounter frank confusion, disorientation, seizures, mutism, profound dementia, coma—and death.

Although abnormal CNS function may never manifest itself or may not become apparent until several months after AIDS is diagnosed, in some patients it develops early in the course of illness. In terms of brain pathology, dementia, when present, is characterized by cerebral atrophy, alteration or loss of nerve cells, and other signs and symptoms. AIDS-related dementia should be suspected in any AIDS patient who experiences marked slowing and decreased acuity of thought.

Laboratory findings may clarify the type or extent of CNS involvement. The electroencephalogram typically shows nonfocal diffuse slowing. Cerebrospinal fluid may show mild protein elevation and altered cells. Computerized tomographic scans may show the cortical atrophy.

Other conditions associated with AIDS, notably toxoplasmosis and primary lymphoma of the brain, can also produce CNS abnormalities. Unlike nonfocal encephalopathy, some of these conditions are amenable to treatment.

Treating Patients

People with AIDS, ARC, and asymptomatic HTLV-III infection typically require many forms of assistance in addition to routine medical care. Among these are the following:

- Referral to local, community-based AIDS service groups.
- Referral to social workers for planning physical and financial assistance.
- Referral to psychiatric staff for monitoring mental status and psychotherapeutic and psychopharmacologic treatment of psychiatric symptoms.
- Mental status examinations to identify altered memory, concentration, orientation, and capacity for abstraction.
- Redefinitions of who may visit to assure that patients are able to see those who are close to them.

People With AIDS

In general, the best treatment builds on the person's past coping abilities, capitalizes on strengths, maintains hope, and shows continued human care and concern. At the time of their diagnosis and throughout the course of treatment, patients should be given up-to-date information about AIDS, its causes, modes of transmission, treatments available, and sources of care

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Treatment of AIDS

Currently, there are no antiviral drugs available anywhere that have been proven to cure AIDS, although the search for such drugs is being pursued vigorously. Some drugs that have been found to inhibit HTLV-III have not led to clinical improvement. Clinical evaluation of other drugs is now under way. Doctors have had some success in using drugs, radiation, and surgery to treat the various illnesses of AIDS patients. Therapeutic agents are needed at all stages of infection, to block action of the virus, and to restore full function in patients whose immune systems have been damaged. Eventually, a combination of therapies to combat the virus and restore the immune system may be the most effective treatment.

and social support. They should also be alerted to common types of misinformation about HTLV-III infection, ARC, and AIDS. Health care professionals must recognize and discuss the patient's fears realistically, but should not give false reassurance.

Suicidal thoughts and plans should be discussed openly to allow the patient to ventilate feelings of despair. Gauging the seriousness of suicidal intent is also important. Staff is justified in becoming ever more alarmed as the patient's suicidal preoccupations gel into concrete plans (especially when a gun or other means are at hand), and when plans are carried out in actual suicide attempts.

Appropriate medications for both anxiety and depression should be considered; because many of these drugs cause drowsiness, they may be administered at bedtime for patients having trouble sleeping. Feelings about homosexuality or drug-taking habits, guilt over being a source of contagion, and anger at discrimination and stigmatization should also be explored. Intravenous drug abusers should be offered treatment.

Patients with progressive disease should also be urged to discuss their feelings about the illness and encouraged to express fear, anger, and depression. They should, of course, be treated with concern and compassion and assured that everything will be done to provide continuity of care and relief from distress. Many patients feel less anxious about upcoming medical procedures when a nurse or other staff member exactly describes what the experience will entail.

For patients who are afraid of being abandoned, frequent visits from friends, families, or health care workers should be arranged. Support groups based on the model of cancer support groups are likely to be beneficial.

In some areas of the country, home care programs provide 24-hour attention and monitoring of symptoms and their associated pain, nausea, and labored breathing. If such programs are available, health care workers may wish to help organize friends and family—whomever the patient feels comfortable with—to provide physical and emotional interventions and support.

The patient's concerns over imminent death should be discussed. The person with AIDS needs the opportunity to call upon clergy for spiritual support, to obtain legal assistance, especially in preparing a will, and to give directions for care during terminal stages, notification of clergy and family, and funeral arrangements. Patients who are rapidly losing mental acuity should be encouraged to appoint a legal guardian as soon as possible, before they are declared legally incompetent.

Transmission of HTLV-III

HTLV-III infection is spread by sexual contact, needle sharing, or, less commonly, through transfusion of infected blood or its components. The risk of acquiring the infection is increased by having multiple sexual partners, either homosexual or heterosexual, and sharing of needles among those using illicit drugs. HTLV-III may be transmitted from infected mother to infant before, during, or shortly after birth (probably through breast milk).

AIDS is difficult to catch, even among people at highest risk for the disease. The risk of transmitting AIDS from daily contact at work, school, or at home apparently is nonexistent. In virtually all cases, direct sexual contact or the sharing of IV drug needles has led to the illness.

Others With HTLV-III Infection

Individuals who have tested positive for HTLV-III antibody and those with AIDS-related complex may require psychological and psychiatric care that is similar to that given people with AIDS. Unlike many who have frank AIDS, however, people with ARC and others with HTLV-III infection usually do not face imminent death. But they have significant problems caused by their ambiguous disease status and the need to make major changes

in their behavior. These patients are not only more likely to engage in sex or IV drug use than are physically debilitated people with AIDS, but they are also probably more infectious as well. Changing established sexual practices or habits of drug use—likely to prolong their own lives as well as protect others—becomes the focus of intense psychological concern.

Persons who have been told that they are positive on the HTLV-III antibody test are likely to experience considerable anxiety. Their fears, like those of high-risk groups in general, focus on the dread of developing AIDS. But because of the objective nature of the antibody testing, fears will probably be more intense. It is essential to point out that a positive test result does not constitute a diagnosis of AIDS, nor does it mean that they will necessarily develop AIDS in the future. They should be told that the positive test result shows that they have antibody to the AIDS virus in their blood. They must be cautioned that the presence of antibody does not give them an immunity to AIDS. (Antibody to HTLV-III does not effectively neutralize the virus.) *They must also be warned that they are presumed to be infectious to others and that they may remain so for life.* They should be encouraged to alert past and present sexual partners, physicians, nurses, and dentists of their antibody status. Health care workers should be alert to the range of psychological reactions a positive finding may provoke and respond sensitively to the variety of possible reactions from patients.

Antibody Testing

The Enzyme-Linked Immunosorbent Assay (ELISA) test, which detects antibody to HTLV-III, is used to screen donated blood and plasma. If the test is positive for HTLV-III antibody, the finding is usually confirmed with a more specific and expensive test—the Western Blot—before a person is definitively considered to have been infected with HTLV-III. Used by blood banks, antibody screening tests make it possible to identify and discard infected blood. Thus, they prevent cases of AIDS resulting from blood transfusions or use of contaminated blood products. Under certain circumstances, the test may be recommended by physicians in order to verify or support a clinical diagnosis. It is available through State or local health departments, and at other sites.

Counseling should begin before the test is given. Full information about the purpose of the test, the meaning of either a positive or negative result, and issues of confidentiality should be addressed. Antibody-reactive patients may fear social ostracism and may anticipate difficulties with employment and insurance through loss of confidentiality of their test results. Blood banks and alternative HTLV-III testing sites have developed codes to protect the identity of positive responders. Whatever procedures are followed at the local site to ensure confidentiality of test results must be thoroughly explained to the person before testing is done.

Although the test itself is objective, its meaning is ambiguous. No one yet knows which infected individuals will go on to develop ARC or AIDS. The person with a positive result will require help in tolerating this ambiguity. A common reaction is denial, which can take the form of avoiding future contact with health care providers. Denying that AIDS is a threat could lead to further risk to other people. Some people with positive test results benefit from psychotherapy or participation in a support group, where they can learn more adaptive ways of coping other than denial.

For people who are HTLV-III positive, somatization, anxiety, and self-doubt often present problems. Those whose psychological distress is expressed in physical symptoms should be asked about their specific fears concerning AIDS (including, for example, illness, pain, abandonment, helplessness, or disclosure of sexual preference or drug abuse). Using this knowledge, patients can benefit from understanding how their fears may be related to past life experiences and present conflict.

In dealing with such problems, the health professional's goal should not be to dismiss fears, but to help patients confront them. Health care workers who are uncomfortable with such demands may refer patients to mental health professionals.

Anxiety may not always be obvious, but rather be expressed as general tension, insomnia, agitation, and lapses in attention. Since information can be a powerful anxiety-relieving tool, it should be readily available and as up-to-date as possible. The patient should be assured that some personal control over the future is possible, principally by avoiding unsafe sexual practices and IV drug use (as recommended by the Public Health Service—see box). Information about safe sexual practices should be provided.

Gay men may need psychotherapy to deal with life-long concerns about sexual orientation awakened by the threat of AIDS. Discussing changes in sexual behavior may be especially difficult for them. Self-help groups made up of individuals with similar concerns may provide needed support.

Patients with a premorbid history of psychiatric illness or suicide attempts will probably need the most extensive mental health care. Health care professionals should be especially watchful for delayed psychological reactions. The full impact of the physical findings may not occur until the person has had time to reflect. Providing telephone numbers where counseling can be obtained is critical.

Prevention of AIDS

Cases of AIDS related to the medical use of blood or blood products are being prevented by use of HTLV-III antibody screening tests of blood donors and by deferring members of high-risk groups voluntarily not donating blood. Treatment of factor VIII and other blood products [illegible] AIDS in patients treated for hemophilia and other clotting disorders.

There is no vaccine for AIDS itself. However, there is good reason to believe that individuals can reduce their risk of becoming infected with HTLV-III by observing precautions based on knowledge of how the virus is transmitted. Communities can help prevent AIDS by vigorous efforts to educate and inform their populations about the illness, with special emphasis on educational activities for members of high-risk groups. Meanwhile, the effort to produce vaccines and drugs against AIDS continues.

The U.S. Public Health Service recommends that the following steps be taken to prevent spread of HTLV-III infection and AIDS:

Recommendations for the General Public

- Don't have sex with multiple partners or with persons who have had multiple partners (including prostitutes). The more partners you have, the greater your risk of contracting AIDS.
- Obviously, avoiding sex with persons with AIDS, members of the risk groups,* or persons who have had a positive result on the HTLV-III antibody test would eliminate the risk of sexually transmitted infection by the virus. However, if you do have sex with a person you think is infected, protect yourself by taking appropriate precautions to prevent contact with the person's body fluids. ("Body fluids" include blood, semen, urine, feces, saliva, and women's genital secretions.)
  - —Use condoms, which may reduce the possibility of transmitting the virus.
  - —Avoid practices that may injure body tissues (for example, anal intercourse).
  - —Avoid oral-genital contact.
  - —Avoid open-mouthed, intimate kissing.
- Don't use intravenous drugs. If you do, don't share needles or syringes.

*Persons at increased risk of HTLV-III infection include: homosexual and bisexual men; present or past intravenous drug users; persons with clinical or laboratory evidence of infection, such as signs or symptoms compatible with AIDS or AIDS-related illnesses; persons born in countries where heterosexual transmission is thought to play a major role in the spread of HTLV-III (for example, Haiti and Central African countries); male or female prostitutes and their sex partners; sex partners of infected persons or persons at increased risk; persons with hemophilia who have received clotting factor products; and newborn infants of high-risk or infected mothers.

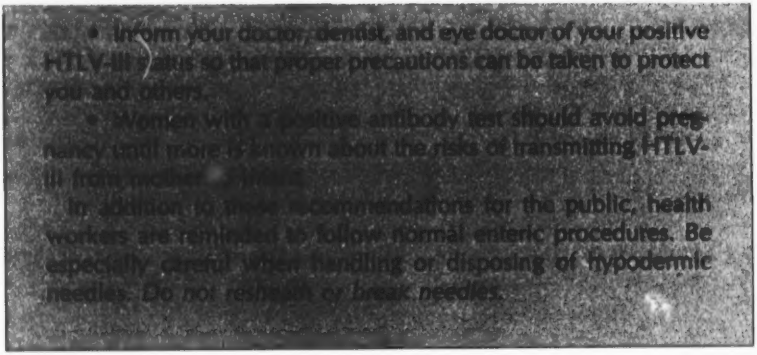
Recommendations for Persons at Increased Risk of Infection With HTLV-III

Those at increased risk of infection should follow the recommendations given above for the general public. In addition, because it is possible to carry HTLV-III without knowing it and thus transmit it to others, the following recommendations should also be heeded:

- Consult your physician for counseling. Consider asking to take the HTLV-III antibody test, which would enable you to know your status and take appropriate actions.
- During sexual intercourse, protect your partner from contact with your body fluids (blood, semen, urine, feces, saliva, and women's genital secretions).
- Don't donate blood, plasma, body organs, other body tissue, or sperm.
- If you are a woman at increased risk, consider the risk to your baby before becoming pregnant. (AIDS can be transmitted from infected mother to infant.) Before becoming pregnant, you should take the HTLV-III antibody test. If you choose to become pregnant, you should be tested during pregnancy.

Recommendations for Persons With a Positive HTLV-III Antibody Test

- Seek regular medical evaluation and followup.
- Either avoid sexual activity or inform your prospective partner of your antibody test results and protect him or her from contact with your body fluids during sex. "Body fluids" include blood, semen, urine, feces, saliva, and women's genital secretions. Use a condom, and avoid practices that may injure body tissues (for example, anal intercourse). Avoid oral-genital contact and open-mouthed, intimate kissing.
- Inform your present and previous sex partners, and any persons with whom needles may have been shared, of their potential exposure to HTLV-III infection. They should receive counseling and antibody testing. Information may be available at local health clinics.
- Don't share toothbrushes, razors, or other items that could become contaminated with blood.
- If you use drugs, enroll in a drug treatment program. Needles and other drug equipment must never be shared.
- Don't donate blood, plasma, body organs, other body tissue, or sperm.
- Clean blood or other body fluid spills on household or other surfaces with freshly diluted household bleach—1 part bleach to 10 parts water. (Don't use bleach on wounds.)


• Inform your doctor, dentist, and eye doctor of your positive HTLV-III status so that proper precautions can be taken to protect you and others.
• Women with a positive antibody test should avoid pregnancy until more is known about the risks of transmitting HTLV-III from mother to infant.
In addition to these recommendations for the public, health workers are reminded to follow normal enteric procedures. Be especially careful when handling or disposing of hypodermic needles. Do not recap or break needles.

Support Groups and Mental Health Referral

When the now familiar pattern of AIDS first became apparent, gay men began forming groups in an effort to cope with the loss of friends. Support groups were developed by organizations such as the Shanti Project in San Francisco and Gay Men's Health Crisis in New York City. These groups have often proved to be the principal source of psychological support available to some people with AIDS.

Because of this experience, many medical facilities have formed support groups of their own, typically modeled after the groups that provide support for cancer patients and their families. These groups often prove of great benefit to patients.

Patients who have just received a diagnosis of AIDS may find a support group too frightening an experience, however. Instead, more informal social settings, especially at first, may provide the structure needed for the patient to resist the tendency to remain isolated.

Experience has shown that support groups should be open-ended, allowing people with AIDS to attend intermittently if they choose. Information gained in the group may make it possible for them to dismiss untrue notions about AIDS. They can learn that, although they have every reason to feel sad, frightened, and angry, they can still control their own attitudes, make their own decisions, and, within limits, manage their own lives. Many learn to participate more actively in their own treatment, contributing to treatment decisions and augmenting medical procedures with attention to diet, adequate rest, exercise, and relaxation.

If not included in the initial treatment, referral for mental health evaluation and therapy should be made if the person's symptoms of anxiety and depression threaten to become disabling and to interfere with treatment of the physical condition. Psychotherapy may help the person with AIDS understand and deal with underlying emotional issues. Judicious and informed pharmacologic treatments also may be helpful in ameliorating acute psychological distress as well as improving symptoms of delirium and dementia. A medication regimen for psychiatric symptoms must, of course, be coordinated with those for physical conditions.

The individual's level of social and psychological functioning prior to contracting AIDS predicts his or her reactions to the disease. It is important to be aware that severe psychological symptoms, maladaptive responses to the stress of AIDS, and suicide attempts are much more likely to occur in the person with a personality disorder (often the case with intravenous drug users) or a prior major psychiatric disorder. Such persons are likely to need extensive psychiatric assistance.

Needs of Health Professionals

Cancer and other diseases associated with fatal outcomes have taught mental health professionals much of what they know about caring for people with AIDS and other types of HTLV-III infection. As with cancer, health care providers need the opportunity to discuss feelings about the vulnerability of their patients. They typically experience anticipatory grief for patients they expect to die, actual grief when patients do die, frustration over their inability to change the course of the illness, and anger over the negative reactions of others.

Workers unused to dealing with delirium and dementia in patients should learn to recognize these signs and symptoms. They must lower their expectations about the patient's ability to adhere to procedures and treatment as mental capacities diminish.

Fears about the transmission of HTLV-III infection still exist among some health care staff. Meetings give staff an opportunity to discuss fears about personal safety, as well as to raise concerns about other issues, such as the drain on institutional resources, organization of AIDS services, and the burden on staff. Support groups for health care workers treating AIDS patients have been found helpful in some settings.

Because patients must feel free to discuss their habits, lifestyle, and sexual preference and practices, health professionals should be able to discuss them comfortably. Staff must know enough about homosexual practices and behavior surrounding intravenous drug abuse to understand the issues and problems as they relate to the transmission of HTLV-III.

Institutions caring for people with AIDS should keep an updated file of AIDS information—mode of transmission, cause, and treatment. The information then can be regularly passed on to staff members, who should also attend local AIDS update courses and request rounds on AIDS at their medical center. The staff is then able, in turn, to keep patients informed of new developments, especially those likely to offer hope.

Conclusion

The emotional well-being of people with AIDS is undermined by physical disease, weakness, and pain, by the likely imminence of death, and by stigmatization, social oppression, and pervasive loss. Those who have AIDS-related complex or who have been infected with HTLV-III but are asymptomatic are subject to intense anxiety and depression, often made worse by self-imposed isolation.

Health care professionals can do much to ease the burden of AIDS patients and others with HTLV-III infection. They should:

- Be alert to the possibility of motor, behavioral, and cognitive changes potentially indicative of compromised brain function resulting from HTLV-III or related infections.
- Focus on the need of the person with AIDS for a strong social support network, including specific AIDS support groups.
- Be responsive to the differing psychological reactions to the various stages of HTLV-III infection, noting particularly the possible tendency for patients with ARC to endure the greatest psychological distress.
- Be aware that caring for fatally ill patients, fears of contagion, and difficulties in working with cognitively impaired patients may undermine the health care worker's ability to respond to the needs of the person with AIDS. Support groups for health care workers dealing with HTLV-III patients and high-risk group members have been found helpful in dealing with these issues.
- Remember that mental health professionals are available. They have been trained to treat the symptoms of people trying to cope with psychological pain. Refer patients who are having particular difficulty. Seek help yourself if you are troubled or overwhelmed by helping people with AIDS.

FURTHER INFORMATION

Recommended Reading

Batchelor, W.F., et al. AIDS. (Special Section, Psychology in the Public Forum.) *American Psychologist* 39(11):1277-1314, November 1984.

Curran, J.W.; Morgan, W.M.; Hardy, A.M.; Jaffe, H.W.; Darrow, W.W.; and Dowdle, W.R. The epidemiology of AIDS: Current status and future prospects. *Science* 229(4720):1352-1357, 1985.

Dilley, J.W.; Ochitill, H.N.; Perl, M.; and Volberding, P.A. Findings in psychiatric consultation with patients with Acquired Immune Deficiency Syndrome. *American Journal of Psychiatry* 142(1):82-86, 1985.

Heller, B.R., issue editor. Acquired Immune Deficiency Syndrome (AIDS). *Topics in Clinical Nursing* 6:19-89, July 1984.

Holland, J.C., and Tross, S. The psychosocial and neuropsychiatric sequelae of the Acquired Immunodeficiency Syndrome and related disorders. *Annals of Internal Medicine* 103(3):760-4, 1985.

Morin, S.F., and Batchelor, W.F. Responding to the psychological crisis of AIDS. *Public Health Reports* 99(1):4-10, 1984.

Nichols, S.E., and Ostrow, D.G., eds. *Psychiatric Implications of Acquired Immune Deficiency Syndrome*. Washington, D.C.: American Psychiatric Press, 1984.

Ostrow, D.G.; Sandholzer, T.A.; and Felm, Y.M., eds. *Sexually Transmitted Disease in Homosexual Men: Diagnosis, Treatment, and Research*. New York: Plenum, 1983.

Pincus, H.A. AIDS, drug abuse, and mental health. *Public Health Reports* 99(2):106-108, 1984.

Snider, W.D.; Simpson, D.M.; Nielsen, S.; Gold, J.W.M.; Metroka, C.E.; and Posner, J.B. Neurological complications of Acquired Immune Deficiency Syndrome: Analysis of 50 patients. *Annals of Neurology* 14(4):403-418, 1983.

United States Conference of Mayors. *National Directory of AIDS-Related Services*. Washington, D.C.: the Conference, February 1986.

United States Conference of Mayors. *Local Responses to Acquired Immune Deficiency Syndrome (AIDS)*. A Report of 55 Cities. Washington, D.C.: the Conference, November 1984.

United States Conference of Mayors. Local experience with HTLV-III antibody testing. *AIDS Information Exchange*, Vol. 2, No. 5. Washington, D.C.: the Conference, August 1985.

United States Public Health Service. *Facts About AIDS*. Spring 1986.

AIDS HOTLINE TELEPHONE NUMBERS

AIDS Hotline
U.S. Public Health Service
Atlanta, Georgia (24 hours, daily)
1–800–342–AIDS

National Gay Task Force (NGTF)
1–800–221–7044 (3 to 9 p.m.)

AIDS INFORMATION FROM STATE DEPARTMENTS OF HEALTH

Alabama — 205–261–5131
Alaska — 907–561–4406
Arizona — 602–255–1203
Arkansas — 501–661–2395
California — 916–445–0553
Colorado — 303–331–8320
Connecticut — 203–549–6789
Delaware — 302–995–8422
District of Columbia — 202–332–AIDS
Florida — 904–488–2905
Georgia — 800–342–2437
Hawaii — 808–735–5303
Idaho — 208–334–5944
Illinois — 312–871–5696
Indiana — 317–633–8406
Iowa — 515–281–5424
Kansas — 913–862–9360
Kentucky — 502–564–4478
Louisiana — 504–342–6711
Maine — 207–289–3747
Maryland — 301–945–AIDS
Massachusetts — 617–727–0368
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Minnesota — 612–623–5414
Mississippi — 601–354–6660
Missouri — 816–353–9902
Montana — 406–444–4740
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